

Seizure Tracker - a Data Resource to Improve Clinical Trial Design

Interagency Collaborative to Accelerate Research on Epilepsy (ICARE)

April 26, 2018

Robert Moss

Co-Founder of SeizureTracker.com
Father to Evan who lives with TSC

seizuretracker.com®
be aware. track it.

login Create a new account
User Name: go
Password:
Forgot User Name/ Password

FREE Pen offer! | News Tracks | Graph Options | Go Mobile | Support the Site | Spread the Word | Printable Logs

what's in store for you

- Free and easy to use online anywhere. [Click here](#) to set up a new account.
- Log and track seizure activity, appointments, and medication schedules through a simple calendar interface from your computer or [mobile phone](#).
- Download printable seizure logs that correspond to the website.
- Customized reports which include graphs comparing seizure activity and medication dosages. [View Sample Report](#)

dedicated.
to providing patients and doctors with free comprehensive tools to help understand the relationships between seizure activity and anti-epileptic medications
[about our mission](#)

first helpful hints
throughout the site
contact us.
info@SeizureTracker.com

Using The Site | About Us | Privacy | Epilepsy Resources

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Free Online

24,000+ Global Users

250+ New Monthly

2,300,000+ Events Logged

1000+ Events Daily

45,000+ Medication Entries

Profile information

Age, gender, diagnosis (patient reported), etc.

Therapies

Medication, Rescue Medication, Diet, VNS, etc.

Logging Apps



Android Mobile
Apple Mobile/Watch (NCH Collaboration)
Alexa Home/Wearables/Etc.

Mobile Interface



Features...

Real Time Seizure Event Logging

Video Capture

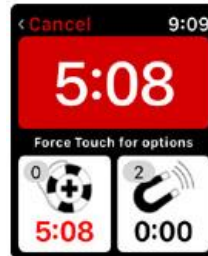
Graphs

Log Offline

Sync At Your Convenience

Easy Access = Better Data

Apple Watch



Accessibility
Nationwide Children's Collaboration
Simple Recording Interface/App Hand Off



Amazon Alexa



Tell Alexa to track your seizures

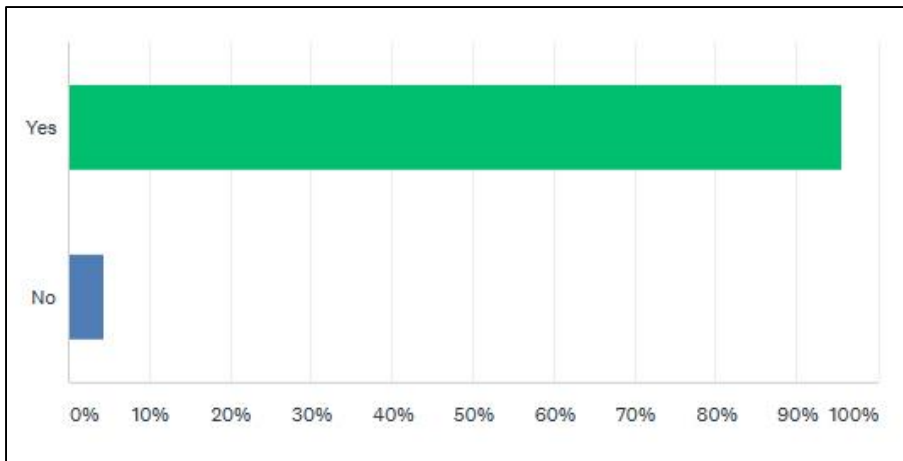


Big Data?

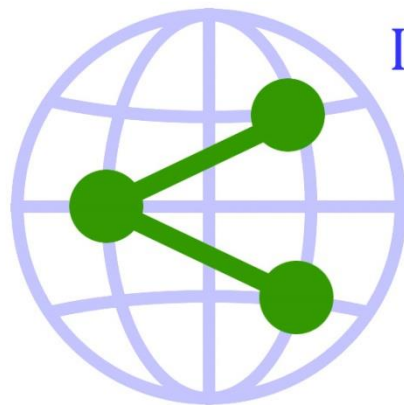
11 Years of Historical Data
2,300,000+ Events Logged
1100+ Events Daily



Research Mandate



Would you be willing to share your anonymous Seizure Tracker data with researchers if you thought it would help develop new treatments for Seizures and Epilepsy?



International
Seizure
Diary
Consortium

Current Projects

Beth Israel Deaconess:

Natural variation

Seizure duration

Placebo Effect

Natural History

Boston Children's

Diurnal variation

Seizure duration

Seizure prediction

Mayo Clinic

Multiscale seizure patterns

Albert Einstein

Cluster properties

Determinants of seizures

Mt. Sinai / NYU

Clinical trial models

Washington University

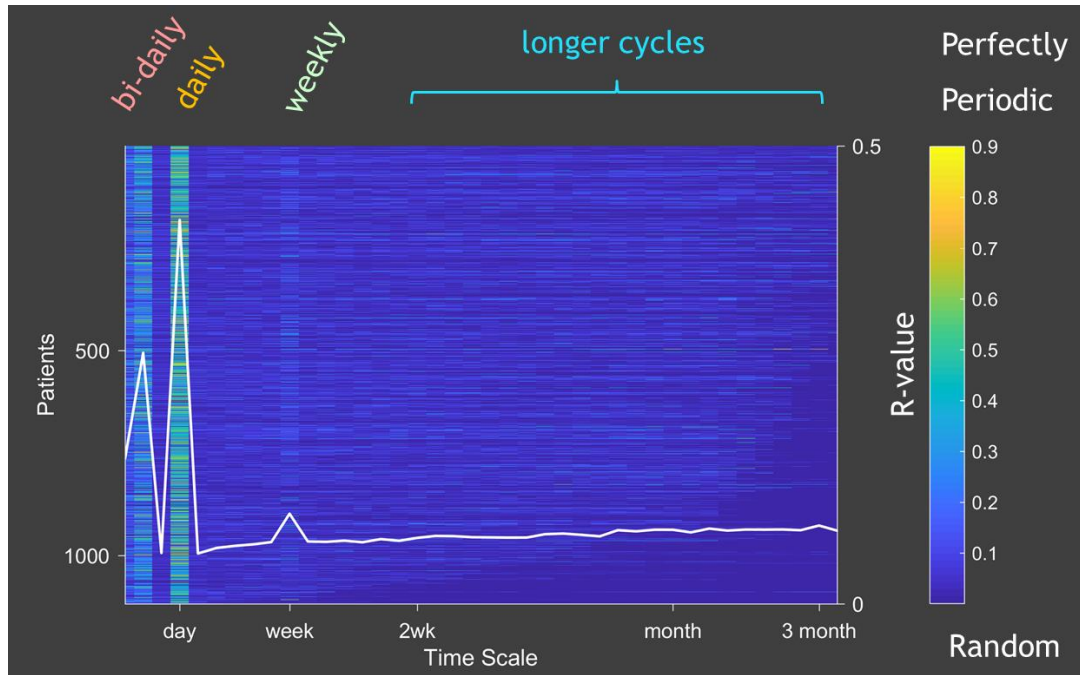
Rational polypharmacy

Melbourne University

Low frequency patterns

www.seizuretracker.com/SeizureSuccess

Multi-day cycles



Circadian and circaseptan rhythms in human epilepsy: a retrospective cohort study
 Philippa J Karoly LANCET NEUROLOGY NOVEMBER 01, 2018

SeizureTracker.com

Self-reported seizures

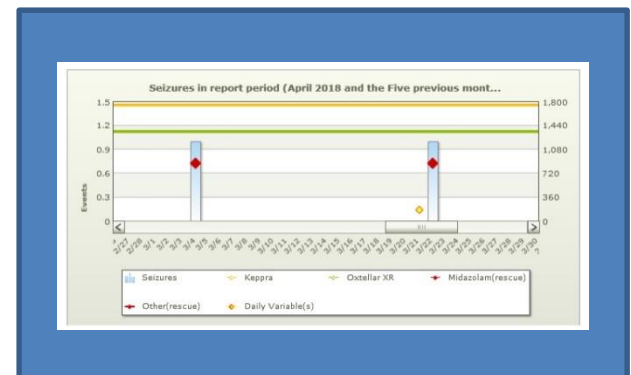
>1000 patients

10 years of recording

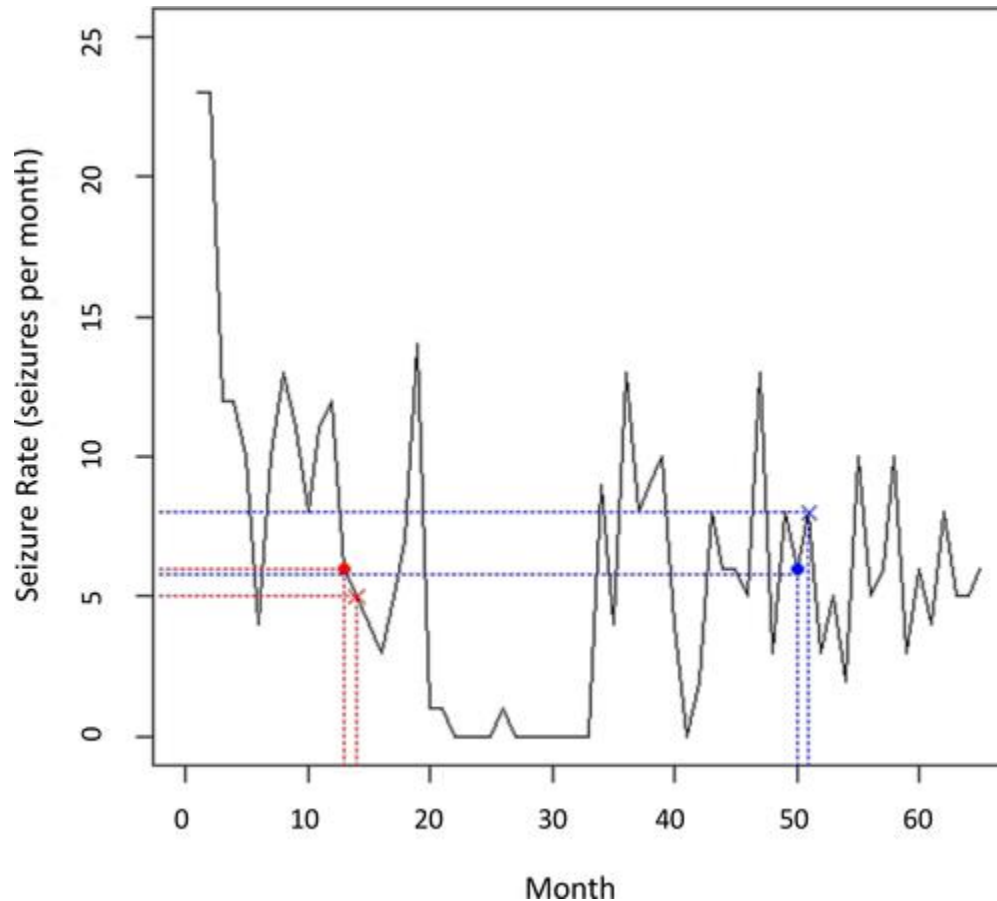
Cycles are highly prevalent

86% circadian

26% 7-day cycle



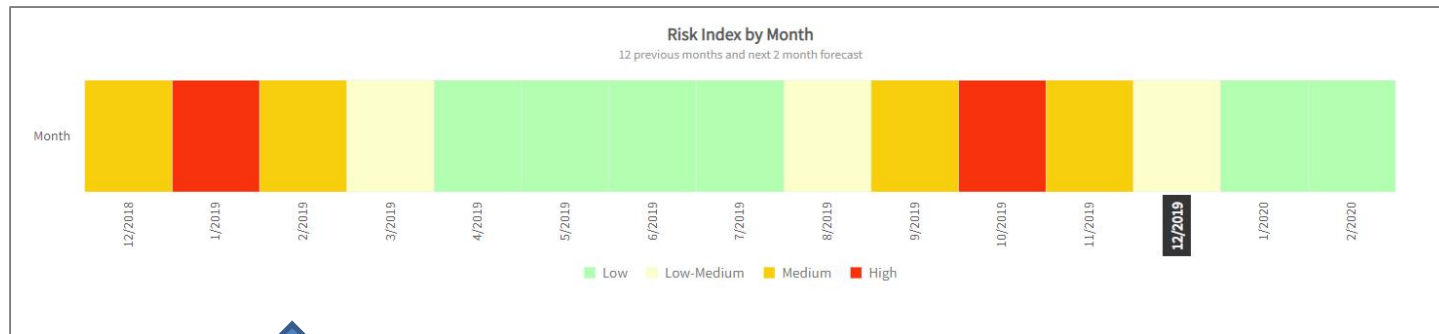
Seizure Risk States



Epilepsy as a dynamic disease: A Bayesian model for differentiating seizure risk from natural variability
[Sharon Chiang](#) March 2018 Epilepsia Open

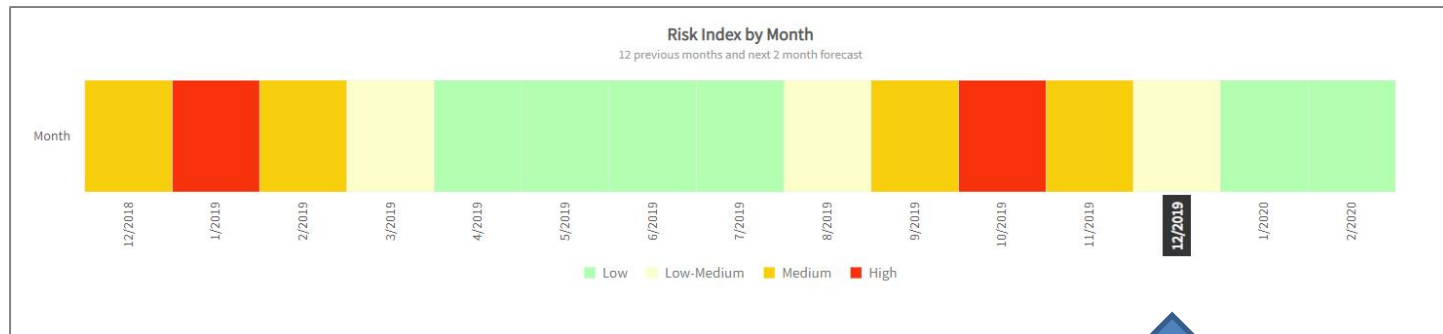
TSC population
Identified four risk states
Transitions/Trajectory

Seizure Risk States



Leverage for timing of enrollment
Understand impact of seizure risk on placebo/therapy

Seizure Risk States

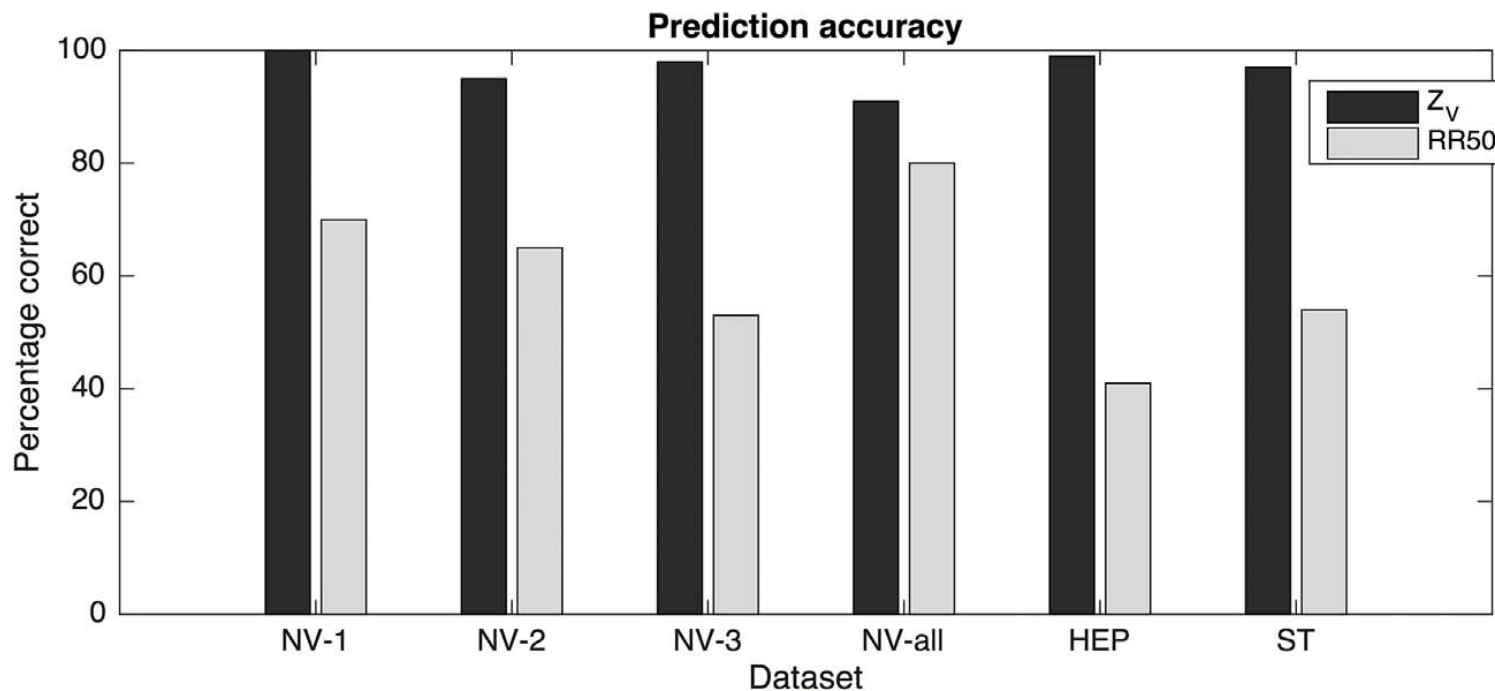


Leverage for timing of enrollment
Understand impact of seizure risk on placebo/therapy

Z_v method

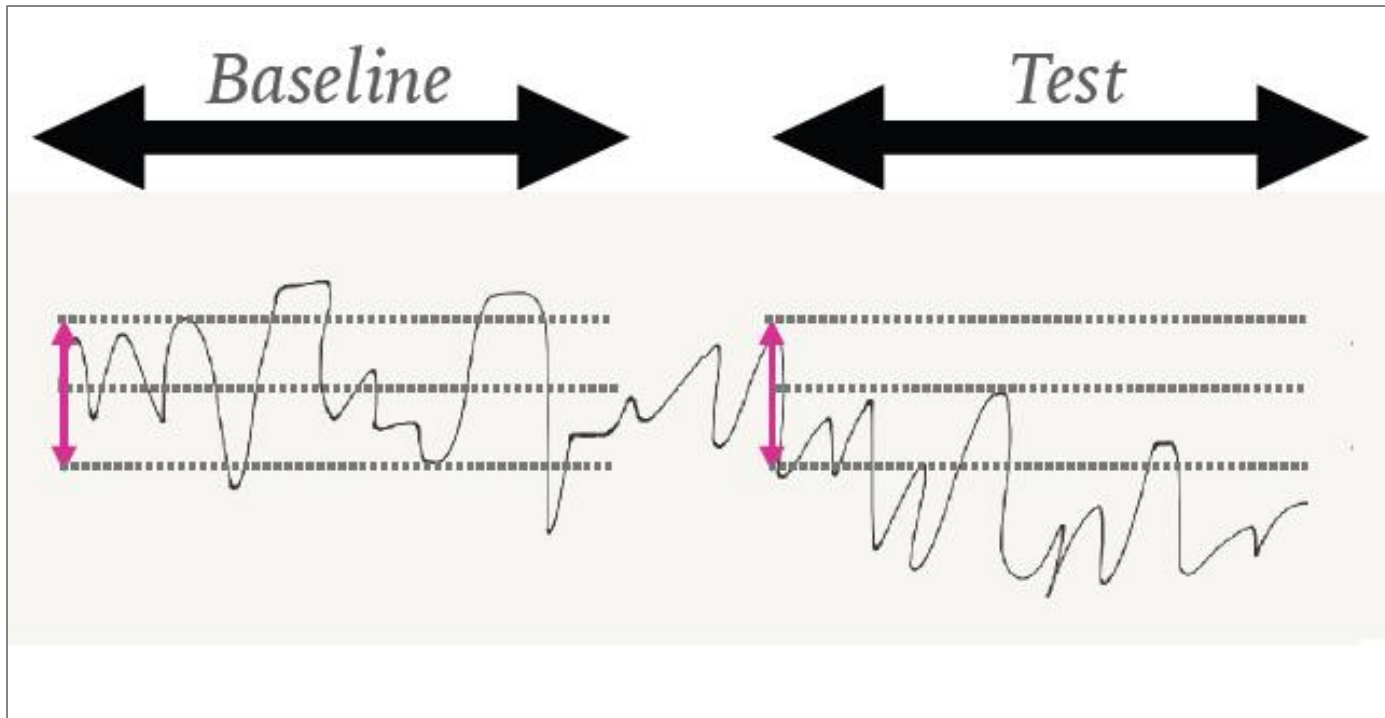
Does accounting for seizure frequency variability increase clinical trial power?

Daniel M. Goldenholz, Epilepsy Research,
November 2017



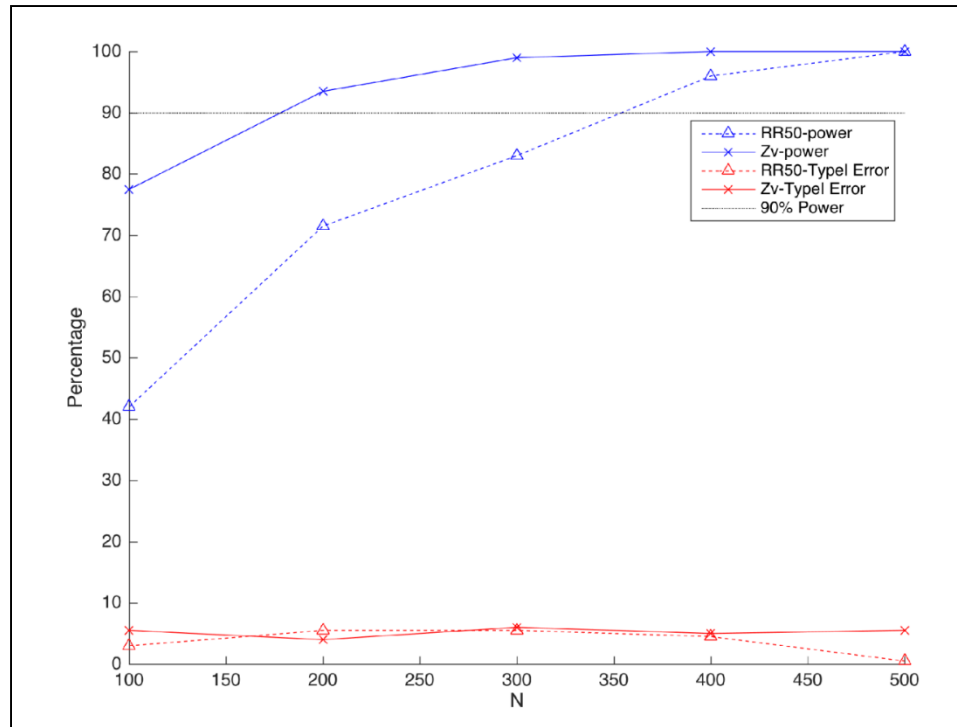
Prediction accuracy across datasets was, Z_v: 91–100%, RR50: 42–80%. Simulated RCT Z_v analysis achieved >90% power at N = 100 per arm while RR50 required N = 200 per arm.

Zv method



- Measure baseline variability
- Establish confidence intervals
- Predict test variability
- Generate normalized Z scores

Zv method



Participant count for 90% accuracy

Potential benefits of electronic diary usage

Individualized profiling/results

More accurate data

Reduce trial size

Possibly eliminate baseline evaluation period

Targeted recruitment

ST Data Share Program/Study management

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be aware. track it.

Thank You!

Contact:

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